

FLOOR STATEMENT
COMPASSIONATE CARE FOR CHILDREN ACT OF 2003
BILL INTRODUCTION
U.S. SENATOR MIKE DEWINE
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Mr. DeWINE. Mr. President, I rise today to discuss a very important issue -- one that is difficult to think about and talk about, but one that is critical to many children and many families in our Nation. What I am talking about is what we do or what we can do when a child develops a life-threatening or terminal illness. What I am talking about is the need to make sure that we can do everything in our power to make sick children as comfortable as possible and as happy as possible -- everything in our power to ease their suffering. What I am talking about is the pressing need for comprehensive, compassionate, continuous care for children who are facing death as the result of serious illnesses -- the need to make palliative care available to any child who is seriously ill.

Mr. President, no parent or family member ever expects a child to die. With today's modern medicine and research advances, it is easy to think that only older people die. Tragically, that is not the case. And that is why, Mr. President, today, along with Senator DODD and Congresswoman PRYCE and Congressman MURTHA, we are introducing a bill -- the Compassionate Care for Children Act of 2003 -- in an effort to help ensure that very sick children receive a continuum of care and that young lives do not end in preventable pain or fear or sadness.

Mr. President, every year, over 55,000 children die in the United States. Some children will die suddenly and unexpectedly -- in a car accident, by drowning, in a fire, or by choking. Some children will be murdered. And others -- thousands of children -- will be diagnosed with a life-threatening illness or a disease that can eventually -- over a period of time -- take their lives.

Children with these kinds of illnesses are in and out of hospitals and clinics. They receive chemotherapy and radiation treatments. They undergo multiple surgeries. They have nurses and doctors poking and prodding at them nearly all of the time. Some of these children are old enough to realize they could die -- that the treatments for their diseases may not work. Others are too young to understand that reality.

One little girl, Liza, knew that she was going to die. Shortly after her fourth birthday, Liza was diagnosed with acute lymphocytic leukemia. For the next year, Liza's parents explored every possible medical option for Liza --

every possible treatment. They took her to doctor after doctor after doctor and had access to the most cutting-edge therapies available to treat Liza's disease.

Nothing seemed to work.

At the age of five, Liza began to ask her mother about what would come next -- whether she would soon die after her bone marrow transplant -- her last chance for a cure -- had failed. Once the medical treatments had failed, hospitals had little else to offer Liza. There was no discussion of end-of-life care at the hospital for the little girl -- no one wanted to admit that they were out of treatment options -- that there was no cure -- that she wasn't going to get better and have her health restored -- that she wasn't going to grow up and become an adult and have her own children someday. No one at that hospital wanted to talk with Liza about death, even though she pleaded with them to do so.

Liza's mother told the *Washington Post* that Liza asked her oncologist to tell her when death was near -- this little five year-old girl, Mr. President, asked her doctor to tell her when she was going to die. Yet, Mr. President, on the final night of her life, as Liza lay dying in her mother's arms, near her father and older sister, Liza asked, "Why didn't the doctor call to tell me?"

Though Liza's parents were able to get some hospice care for their daughter during the last three months of her life, tragically, fewer than 10 percent of children who die in the United States ever receive any sort of hospice care. When children, like Liza, are terminally ill, parents are forced to make decisions for their children under extremely emotional and stressful conditions -- and the decisions that confront these parents are ones that they never expected to face.

Parents want what is best for their children. They want their children to get better and be healthy. They want their children to be pain-free. They want their children to receive comfort and care when they are sick. And God-forbid parents find out that their children are very sick -- so sick that they are never going to get better -- so sick that there are no more treatments and no cures -- so sick that they know their children are going to die -- those parents will try to do everything imaginable -- everything possible in their power -- to help their children and make them comfortable and pain-free and happy in their remaining days.

Mr. President, children with life-threatening diseases and illnesses require special medical attention to make their shortened lives more comfortable. We know that. Yet despite that knowledge, current federal law and regulations do not take into consideration the special care needs of a

gravely ill or dying child. The legislation we are introducing today would help correct for the deficiencies in current law and help sick children facing possible death live in comfort and with dignity and comprehensive care.

Let me take a few moments, Mr. President, to explain what our bill does. First, it offers grants, so that doctors and nurses can receive training and education to enable them to provide end-of-life care to children. The goal of these grants is to improve the quality of palliative care that terminally ill children receive.

Our bill also provides money to the National Institutes of Health to conduct research in pain and symptom management in children. This research is critically important to improve the type of care dying children receive. A recent article in the *New England Journal of Medicine* stated that 89% of children dying from cancer die experiencing "a lot or a great deal" of pain and suffering. This is not acceptable, Mr. President -- research should be done so that children do not suffer needlessly.

In addition to grants, the second piece of our bill changes the way care is delivered to children with life-threatening illnesses. Right now, doctors, hospitals, and parents have to overcome significant insurance and eligibility barriers to enroll a dying child in hospice. First, to qualify for hospice, a doctor must certify that a child has six months or less left to live. The problem with this "six month rule" is that it is harder for a doctor to determine the life expectancy of a sick child than it is to determine the life expectancy of a sick adult or elderly person. A child dying of cancer, for example, may die in six months or six years, making that child ineligible for hospice care that would ensure a comfortable life while that child is alive.

According to Dr. Joanne Hilden and Dr. Dan Tobin, "Sick children are still growing, which is a biological process very much like healing. So, when a child is diagnosed with an illness such as cancer or heart disease, he is much more likely to be cured than is an adult." Simply put, diseases progress differently in children than adults, and children with terminal diseases get lost in a health care system designed for adults -- a health care system that does not take into consideration the special needs of children.

Furthermore, the current system does not allow a patient to receive curative and palliative care simultaneously. In other words, current law does not allow doctors to continue trying life-prolonging treatments-- treatments that could cure an illness or extend a life -- and provide palliative care to that patient at the same time. And that is tragic, Mr. President, because palliative care offers a continuum of care -- care that involves counseling to families and

patients about how to confront death -- care that involves making the patient comfortable in his or her sickest hours -
- care that acknowledges that death is a very real possibility.

Federal law requires a person who wishes to receive end-of-life care to discontinue receiving curative or life-prolonging treatment. When a child is involved, this means that parents must agree to no longer provide curative treatments in order for their child to receive care and support for the possible end of life. This should not be an "either or" decision for parents, Mr. President. I don't know of any parent who would ever give up trying to cure a sick child or prolong that child's life in order to receive end-of-life care. Current law places parents in impossible positions, Mr. President, and we need to fix this.

End-of-life care should be integrated with curative care, so that parents, children, and doctors have access to a range of benefits and services. As I said already, Mr. President, palliative care should not be confined to the dying -- it should be available to any child who is seriously ill. That is why our bill creates Medicare and private market demonstration programs to remove these barriers, making it simpler and easier for both doctors and parents to make end-of-life decisions for children. The demonstration program would allow children to receive curative and palliative care concurrently. This means children can continue to receive treatment and life-prolonging care while receiving palliative care at the same time. The demonstration program also removes the "six-month rule," so children can receive a palliative care benefit at the time of diagnosis.

Mr. President, I'd like to take a moment to tell my colleagues about another little girl -- Rachel Ann. Rachel Ann was a little girl who did receive palliative care from the time she was diagnosed with a grave heart problem. Rachel Ann had a heart that doctors described as "incompatible with life." Most babies with heart malformations, like Rachel Ann's, die within a matter of days after birth. Her parents were naturally devastated and distraught at seeing their tiny baby connected to a sea of wires and tubes, clinging to life.

Rachel Ann's parents were referred to a pediatric hospice and decided to bring their daughter home from the hospital so that she could experience life with her family, surrounded by her parents, brothers, relatives, and church community at home. Rachel Ann's parents say that she seemed truly happy at home. She smiled and wriggled in response to voices and to being held. Her brothers doted on their baby sister.

Rachel Ann was able to spend her life at home, in comfort, with her family. She lived for 42 days and her family was

able to make every single moment count. On Christmas day, after spending the morning with her family, Rachel Ann passed away.

Mr. President, this is a tragic story. But fortunately, Rachel Ann and her family were able to spend as much time together as possible, with Rachel Ann as comfortable as possible. Her brothers were able to know their sister and to talk with hospice professionals about what was happening to her. Rachel Ann's parents and grandparents also were able to talk about her condition with hospice professionals and maintained an active role in her care. There was a support system in place for this family in grief.

Mr. President, the terminal illness of a child must be an incredibly difficult thing to confront for a parent and a family. No one wants to think about children dying. No one wants to believe that children suffer, especially in this age of great medical advances. It is a horrible situation, but it is one that we must face.

We can always do more to improve the care that our children receive. We should continue to support research in finding cures for the diseases and illnesses from which children suffer. But, until those cures are found -- and as long as children die from these diseases -- we must provide care and support for a dying child. We have an obligation to provide that care and that support.

Our bill would be an important step in this direction, Mr. President. It would provide tools and support networks to help grieving families in their time of need. It is the right thing to do, and I encourage my colleagues to join us in co-sponsoring this important legislation. I thank the Chair and yield the Floor.